Monday, June 5, 2017
Room Location: Phillips Ballroom
Kimpton Hotel Palomar

7:30 AM  Breakfast and Registration Open

8:30 AM  Welcoming Remarks
Natasha Bonhomme, Genetic Alliance
Joan Scott, Health Resources and Services Administration

9:00 AM  General Session
Lessons Learned Through Public Health & Newborn Screening Education and Engagement
Kristen Thompson, Michigan Department of Health and Human Services

The Why in Newborn Screening Education and Engagement
Kimberly Piper, Iowa Department of Public Health

Understanding the Best Practice Continuum
Kelly Umaña, Association of Maternal and Child Health Programs

10:15 AM  Break

10:30 AM  Breakout Workshops
The Who in Newborn Screening Education and Engagement

Workshop A: Engaging Families
Identifying potential best practices in getting messages to families and the public when there are “competing” priorities for their time

Location: Phillips Ballroom
Facilitators:  Carol Johnson, Iowa Newborn Screening Program
             Janice Freedman, North Carolina Healthy Start Foundation
**Workshop B: Priority/Target Populations**

*Identifying priority populations and populations underserved by existing health and newborn screening systems; identifying potential best practices in reaching these populations*

**Location:** Freer

**Facilitators:** Joyal Meyer, *North Dakota Department of Health*

Maria Isabel Frangenberg, *Family Voices National*

**Workshop C: Engaging Health Educators & Health Professionals**

*Identifying how to form partnerships with health educators/professionals and have them be allies in educating about newborn screening*

**Location:** Corcoran

**Facilitators:** Frederick Chen, *University of Washington*

Andrea Goodman, *Genetic Alliance*

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11:30 AM  **Workshop Report Back**

12:00 PM  **Lunch (provided)**

1:00 PM  **General Session**

*Family Perspectives*

Jackie Seisman, *Genetic Alliance*

2:00 PM  **Breakout Workshops**

*The When in Newborn Screening Education and Engagement*

**Workshop A: Prenatal vs Postnatal**

*Identifying needs and approaches to educating in these timeframes – similar audiences, different priorities*

**Location:** Freer

**Facilitators:** Sarah Verbiest, *UNC Center for Maternal and Infant Health*

Elizabeth Rochin, *Association of Women's Health, Obstetric and Neonatal Nurses*

**Workshop B: Training and Communications with Healthcare Providers**

*Identifying potential best practices that improve health professionals understanding of the newborn screening system; what do health providers need to know, and when do they need to share it with families?*

**Location:** Phillips Ballroom

**Facilitators:** Johnna Watson, *Maryland Department of Health*

Stacy Hines-Dowell, *St. Jude Children’s Research Hospital*
**Workshop C: Short-term Follow-up**

Identifying potential best practices in communicating with families; what should be focused on when follow up is needed but families are un/under informed?

- **Location:** Corcoran
- **Facilitator:** Amy Gaviglio, Minnesota Department of Health

3:00 PM **Workshop Report Back**

3:30 PM **Break**

3:45 PM **Breakout Workshops**

*The How in Newborn Screening Education and Engagement*

**Workshop A: Priority Setting in Education/Getting Buy-In**

Identifying potential best practices in establishing buy-in for education; how do you prioritize education when it is undervalued or underfunded?

- **Location:** Phillips Ballroom
- **Facilitator:** Sondi Aponte, Arizona Department of Health Services

**Workshop B: Access Issues**

Identifying issues with accessing education and services within the health and newborn screening systems; identifying potential best practices in increasing access to education and services

- **Location:** Freer
- **Facilitators:** Luisa Soaterna, ZERO TO THREE  
  Amy Gaviglio, Minnesota Department of Health

**Workshop C: Education in a Crisis**

Identifying potential best practices when educating during a crisis; how do you engage with families?

- **Location:** Corcoran
- **Facilitator:** Alena Egense, University of Maryland Genetics

4:45 PM **Workshop Report Back**

5:15 PM **Concluding Remarks**

Natasha Bonhomme, Genetic Alliance

*Dinner on your own*
Thursday, June 6, 2017
Room Location: Phillips Ballroom
Kimpton Hotel Palomar

7:30 AM  Breakfast and Registration Open

8:30 AM  Opening Remarks/Recap from Day One
Educating in an Evolving System
Natasha Bonhomme, Genetic Alliance

9:00 AM  General Session

Evaluation of Education & Engagement
John Richards, National Center for Education in Maternal and Child Health

Presenting Best Practices from Day One
Natasha Bonhomme, Genetic Alliance

10:00 AM  General Session
Challenges for (rapidly approaching) Future of Newborn Screening

Communication Technologies and Regulations
Dixie Baker, Martin, Blanck and Associates

Privacy and Autonomy in Public Health
Bob Gellman, Privacy and Information Policy Consultant
Natasha Bonhomme, Genetic Alliance

New Disorders
Alex Kemper, Duke University

10:45 AM  Roundtable Discussions
Peer to peer discussion on needs and approaches to the evolving newborn screening systems in relation to:

Communication Technologies and Regulations
Room Location: Freer

Privacy and Autonomy in Public Health
Room Location: Corcoran

New Disorders
Room Location: Phillips Ballroom
11:30 AM  Break

11:45 AM  Roundtable Report Back

12:30 PM  Working Lunch: Moving Forward- What's Next?
          Recommendations for the Clearinghouse
          Jackie Seisman, Genetic Alliance

1:30 PM  Concluding Remarks
          Natasha Bonhomme, Genetic Alliance

2:00 PM  Conclusion of Summit